



Turning Challenges into Opportunities: A Conversation with Patient Living with Dialysis and His Path to Entrepreneurship

Editor's note: This discussion between Dr. Aditya Pawar, a transplant nephrologist at Beth Israel Deaconess Medical Center (BIDMC) and an Instructor in Medicine at Harvard Medical School, Boston, USA, and Mr. Kamal D Shah, a patient living with dialysis and an entrepreneur, explores the role of patient experience as a catalyst for enhancing healthcare. Together, they discuss the intersection of personal experience and professional practice, offering insights into how patient-driven insights can foster broader improvements in the healthcare system.

Aditya Pawar (AP): Thank you for taking the time to share your journey with us. Can you begin by giving us a background on your experience with kidney disease and where you stand today?

Kamal Shah (KS): Certainly. My journey began in 1997, right after I completed my chemical engineering degree. I was preparing to fly to the US for my Master's. I was vaccinated against Typhoid, Hepatitis B, and Measles, Mumps, Rubella (MMR). That very evening, I developed severe symptoms, which ultimately led to the discovery that my kidney function was impaired. It turned out that I had a genetic mutation causing atypical hemolytic uremic syndrome (aHUS), and the vaccines triggered the disease. I was put on dialysis, first through an arteriovenous shunt, and later through an arteriovenous fistula. Although my nephrologist initially hoped it was a temporary condition, I eventually progressed to kidney failure. My nephrologist tried everything possible to treat me, including plasma infusions, plasmapheresis, and steroids, but nothing seemed to work. About a year and a half later, I received a kidney transplant from my mother. At that time, genetic testing for aHUS was not yet available, which

is why she was chosen as the donor by default. Back then, not much was known about aHUS, and without genetic testing, a mother would typically not be allowed to donate today.

Since then, I have undergone various forms of dialysis. I switched to peritoneal dialysis (PD), which significantly improved my quality of life. In 2004, while on holiday, I was caught in the infamous tsunami and found myself neck-deep in the ocean. A few days later, an infection (*Pseudomonas aeruginosa*) was detected at my exit site, which spread to the tunnel and eventually to the peritoneal cavity. My nephrologist did everything possible to help me to continue PD, which I had been on for 6 years by then, but repeated infections ultimately forced me to give it up. In 2006, I switched to home hemodialysis, which allowed me to regain a sense of normalcy.

I have been on daily nocturnal home hemodialysis for 17 years now, and I'm waiting for a complement inhibitor to become available in India at a reasonable price so I can have a successful kidney transplant.

AP: Can you describe the specific challenges you faced in setting up and maintaining home hemodialysis?

KS: It was pretty challenging to set up a home hemodialysis system. What was unnerving was that while I found people doing conventional twice-weekly or thrice-weekly four-hour hemodialysis sessions at home, I could not find anyone doing nocturnal home hemodialysis. I found an excellent technician and asked him to come home and help with my dialysis. We bought a water treatment plant and set it up on the terrace, where we built a small room specifically for this purpose. The plumbing and electrical fittings were also

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installed. We set up a manual dialyzer reprocessing system and consulted with biomedical engineers and technicians on each aspect. There was no other model to follow—we were in uncharted territory.¹ However, with help, we managed to set everything up and started.

Initially, we encountered many problems with the water treatment plant. After a few weeks, it started malfunctioning, and unfortunately, the manufacturer did not have a local presence. Eventually, we replaced it with a plant from another company. Thankfully, this one worked much better and did not cause further issues.

I also had a couple of incidents of blood loss from the needle sites—one of which was quite significant. I contacted fellow home hemodialysis patients online and learned about a blood leak sensor manufactured in New Zealand. I ordered three of these devices and began taping one each next to each cannulation site, with another placed below the dialyzer. Any blood leak would trigger an alarm, allowing us to address the issue promptly. I also started tying my hand down to limit movement during the session. These measures helped prevent any further blood loss.

Encouraged by patients in other countries in support groups on home hemodialysis, I eventually learned how to cannulate myself. This gave me immense confidence and freedom, as I no longer had to rely on a new technician when the regular one could not be there.

Since this was new to us, we had to figure out solutions as problems arose. We received a lot of support from fellow patients online in other countries, as well as my nephrologist, who oversaw the overall prescription and testing to ensure the therapy was adequate and that I could maintain a good quality of life.

AP: Your journey has had many ups and downs. As someone observing your life, I cannot help but notice your resilience. How do you maintain your morale, and what gives you the strength to continue?

KS: I see my journey as unfolding in three phases. Initially, after being diagnosed, I was determined to find a way out, a path back to normalcy. The transplant seemed to be the solution, and I was hopeful it would restore my everyday life. But when it failed, I was dejected. After an initial period of despondency, I regrouped and told myself I would not let this disease defeat me. I turned to the internet, connected with fellow patients around the world, joined support groups, and educated myself on possible treatments. That's when I learned about PD. I liked what I read about PD. I could do it at home on my own. There would be no needles, no hospital visits, and no complications during the dialysis session. It almost seemed too good to be true. I wondered how I had not even heard about this modality till then. I asked my doctor if I could switch to PD, and after getting his concurrence, I made the

switch. But when I could not continue with PD anymore, I had another conversation with my nephrologist. He saw I could see that I missed the freedom I had with PD, so he suggested Daily Nocturnal Home Hemodialysis. Each setback was just that—a temporary obstacle. I always focused on finding the next solution to regain an everyday life. And thankfully, I have been blessed with a nephrologist who supported me immensely in this journey.

Regarding strength, the desire for normalcy was my driving force. I did not want to live a bedridden or depressed life. I yearned for a simple, comfortable existence with as few restrictions as possible—things like working, traveling, and spending time with family and friends. These simple pleasures kept me going, and I always sought ways to achieve them.

Normalcy is a highly underrated concept. Healthy people do not value it as much. Normal is supposed to be boring. However, as a dialysis patient, all I craved was a normal life—a simple, everyday life. This quest for normalcy drove me to find solutions to my problems at each stage.

AP: Did you observe any limitations in patient care or infrastructure?

KS: There are definitely areas where technology and treatment options are more advanced abroad. For example, during a recent trip to the US, I trained on the NxStage portable dialysis machine², which provided me with tremendous flexibility. Such technology isn't yet available in India, allowing me to travel to places like Yellowstone, where dialysis centers are sparse. Despite the recent strides, access to quality healthcare is not freely available to the majority, especially those living in rural areas. Indian healthcare is rapidly improving, with excellent doctors and world-class facilities in many cities. Specifically, many states have begun providing dialysis to patients completely free of charge. The quality of dialysis is also gradually improving, even in dialysis centers at government hospitals and charitable trusts. Much of this progress is due to new projects being outsourced to private providers, with strict quality criteria enforced through the "Quality and Cost Based Selection" (QCBS), rather than purely tendering based on cost alone.

AP: You've also ventured into entrepreneurship. Can you tell us about that journey?

KS: I believe my entrepreneurial spirit comes from my Gujarati roots, but my journey as an entrepreneur truly began when I found stability with home hemodialysis. It was then that I realized there were many ways dialysis care in India could be improved—whether by offering patients more treatment options or creating more cheerful, patient-centric dialysis centers.

In 2007, I started a blog to share my experiences, quickly gaining popularity among kidney patients and nephrologists in India. One day, I got an email from Vikram Uppala, co-

founder of Nephroplus, who had just returned from the US and was looking to explore healthcare opportunities in India. He had come across my blog while researching ideas and was intrigued by what he read. We met, brainstormed, and eventually co-founded NephroPlus, to improve dialysis care delivery in India.

AP: That's an inspiring story. What is the current state of dialysis in India, and what options do patients have?

KS: The dialysis ecosystem in India is improving year by year. When we started, only about 30% of our patients received weekly dialysis thrice. That number has now increased to about 43%. Many Indian patients still do not receive the recommended number of dialysis sessions due to limited access to dialysis centers and affordability, especially in rural areas. However, awareness of the importance of dialysis access is improving, and today, about 75% of our patients are on an AV Fistula or an AV Graft.

There are three main payment modes for dialysis in India: out-of-pocket, private insurance, and government subsidies. About 30-40% of our patients still pay out of pocket, 10-12% have private insurance, and the government subsidizes the rest. However, individual health insurance policies in India typically do not cover dialysis; it is only covered under group insurance policies. Governments are increasingly getting involved in dialysis through the Public-Private Partnership model. In this model, the government provides dialysis free of charge to patients by paying private providers for the treatments. Even where the government provides free dialysis (both HD and PD), uptake remains limited, mainly due to lack of awareness and other constraints such as the need to travel long distances to access these facilities, caregiver time, and so on.

The quality and accessibility of dialysis vary widely depending on location. While many dialysis centers exist in large cities, access to quality can differ significantly from one center to another. In rural areas, access to quality dialysis is even more challenging. However, the government is partnering with private providers to establish dialysis clinics in rural regions, ensuring that patients receive good quality care at no cost. Quality is typically improved through various measures such as adopting clinical protocols audited by quality auditors, training staff on best practices like infection control, tracking clinical outcomes, incentivizing teams for good outcomes, and so on.

AP: What opportunities for improvement do you see in the future to enhance the quality of dialysis care?

KS: Until recently, there was little oversight in dialysis care. However, in the last few years, the government has begun introducing quality metrics in the tendering process. Providers must prove that they deliver quality care through

tracked metrics. Standards are being implemented for dialysis centers, covering areas such as water quality, clinical outcomes, and other relevant parameters. While it's still in the early stages, we are working to ensure that high-quality dialysis is both recognized and incentivized.

AP: How has your experience as a patient shaped care at dialysis centers?

KS: My experience has been our mission's foundation—enabling dialysis patients to lead normal lives. Many people believe that life on dialysis means a compromised existence, but that doesn't have to be the case. We have launched several initiatives to spread this message. Being on dialysis should not restrict you from playing a sport, so we organize a Dialysis Olympiad, where patients can compete in sports events. I also love to travel and believe dialysis should not keep you from enjoying a good vacation. To encourage our patients to travel, we started a holiday dialysis program allowing them to travel while we care for their dialysis needs. These initiatives are designed to show that life on dialysis can be fulfilling and as close to normal as possible. Of course, providing quality dialysis remains the bedrock upon which all these initiatives are built. What is encouraging is that this emphasis on patient engagement is increasingly being recognized in nephrology.

AP: Running a business in healthcare must come with its challenges. What were some of the biggest hurdles you faced?

KS: Vikram and I came from middle-class families and did not have substantial personal funds to invest in the company. It was Vikram's family and friends who provided the initial capital. With that funding, we started the first three centers. Initially, as non-medical professionals trying to set up a dialysis center, nephrologists did not take us seriously. But we persisted, and through our earnest efforts, we gradually gained the trust of both nephrologists and patients. Over time, nephrologists began investing in the centers they managed, becoming co-owners. They were encouraged by the positive feedback from patients who tried our services. They genuinely appreciated our patient-centric approach—high-quality dialysis, a cheerful ambience, expert staff, and ease of access.

Scaling the network came with its challenges. In India, every state has its unique dynamics. The North is very different from the South, and we had to adapt each time we expanded into a new region.

Staffing has been another significant challenge. Finding well-trained, qualified staff can be challenging. To address this, we set up a training academy called Enpidia in 2012, where we trained technicians and nurses in the technical and empathetic aspects of dialysis care. Today, many training courses for dialysis personnel are supported by the government, which is a promising step forward.

AP: What are your long-term goals for your personal journey?

KS: I'm eagerly waiting for access to complement inhibitors in India so that I can have a successful kidney transplant. Two clinical trials are underway in the country, and Soliris will soon be available in India as well. For the first time, aHUS patients can see a ray of hope for access to these drugs. While the pricing remains unknown, there is hope that a path to a successful kidney transplant may soon be visible.

AP: What changes would you like to see in the dialysis industry in the next five to ten years?

KS: I'd like to see more progress towards home dialysis – both hemodialysis and peritoneal dialysis, where smaller, portable machines are becoming the norm. This would give patients more flexibility and control over their treatment, leading to better outcomes. Several new devices are currently under development that could make this a reality, and I'm hopeful they will become available soon.

AP: Lastly, what advice would you give aspiring entrepreneurs, especially those in healthcare?

KS: My advice is to think big. When Vikram and I started, we were clear that we wanted to build a large chain of dialysis centers, not just a handful. Also, focus on the impact of your work rather than just making money. Often, if you're passionate about the effect you're creating, the financial rewards will follow. Building a solid network is crucial, as is finding a good partner who complements your skills.

AP: In your experience, how important is the patient's voice in shaping the healthcare process?

KS: The patient's voice is absolutely critical in shaping a more user-centered healthcare process. As patients, we

are the ones experiencing the treatments, the challenges, and the day-to-day realities of living with a condition. When we are involved in the design and decision-making process, the outcomes are invariably better because the solutions are tailored to actual needs. It is evident how incorporating patient feedback into services—whether it's the atmosphere in the centers or the flexibility of treatment schedules—has dramatically improved patient satisfaction and outcomes.

I would encourage patients to not only participate in their care but also to consider playing a larger role, whether it's through advocacy, patient advisory boards, or even starting small initiatives that can lead to bigger changes. Starting small is powerful. My journey began with a simple blog, and it grew into something that has significantly impacted dialysis care in India. Every voice matters, and when patients share their experiences and insights, it leads to more compassionate, effective, and patient-centered care.

AP: Thank you, Kamal, for sharing your incredible journey and insights. Your story is truly inspiring and offers valuable lessons for patients, healthcare professionals, and entrepreneurs alike.

KS: Thank you for allowing me to share my story. I hope it helps others in their journey, whether as patients or as entrepreneurs.

Conflicts of interest

There are no conflicts of interest.

References

1. Shah KD, Taking the uncharted path, Am J Kidney Diseases 57;1:A21-3
2. Clark WR, Turk JE Jr. The NxStage System One. Semin Dial 2004;17:167-70.